DOCUMENT RESUME

ED 284 405 EC 200 223

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TITLE Chronically Ill Children: Divisions of Labor.
PUB DATE Jun 86
NOTE 26p.; Paper presented at the Conference of the Association for the Care of Children's Health (San Francisco, CA, June 8-10, 1986).
PUB TYPE Speeches/Conference Papers (150) -- Reports - Descriptive (141)

EDRS PRICE MF01/PC02 Plus Postage.
DESCRIPTORS Childhood Attitudes; Child Rearing; *Decision Making; *Diseases; Elementary Education; Injuries; Interviews; Longitudinal Studies; Medical Services; Observation; Parent Attitudes; *Parent Role; Peer Relationship; Prevention; Qualitative Research; Self Care Skills; *Special Health Problems
IDENTIFIERS *Division of Labor (Household)

ABSTRACT

(A division of labor model was applied in a study of the efforts to minimize health crises and maximize benefits of medical protocols in eight families, each with a hemophilic school-age boy. Subject families were studied for a 5-year period through participant-observer techniques including interviews with the children in their homes, with the mothers, most of the fathers, several of the siblings, school teachers, and health care providers. Analysis of interview transcripts and process notes on observations found two distinctive but linked categories related to division of labor: (1) who in the family becomes central in decision-making and responsible for the home-based medical work; and (2) when (in the children's development) shifts in management occur. Interview excerpts and discussion are organized into the following section titles: "Becoming Medical Technologists at Home"; "Becoming Peer Group Members Away from Home"; and "Siblings' Work--Further and Concurrent Divisions of Labor." Noted in the summary are such differences between parents and children as the importance of protection from physical injury (for the parents) and the importance of peer group relationships (for the children). (DB)

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Chronically Ill Children: Divisions of Labor

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San Francisco, CA, June 8-10, 1986

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CHRONICALLY ILL CHILDREN: DIVISIONS OF LABOR

The concept "division of labor" generally calls to mind an economic, even industrial paradigm, with images of assembly line systems, each worker contributing a vital, albeit small part to a total product. This model in industrial arenas, initially considered "innovative", became a fundamental principle of industrial organization. Durkheim's discussion of "organic solidarity" elaborated on the phenomenon, yet focused on interdependence in this and other aspects of social life [1]. Thus there was a paving of the way for sociological understanding of interactions, though division, in labor. Foucault's premises relative to medical work provided a reorientation in this thinking, highlighting the individual as the object of such work [2].

Social scientists have long examined such divisions and interactions in medical work with the patient as object [3-5]. Efforts to understand medical work with the patient as participant are perhaps relatively rare [6-10]. Ethnographic accounts of unpaid labor which describe how health and illness care is defined and divided within families of given cultures have provided additional perspectives [11].

In contemporary divisions of labor in medicine, particularly between paid and unpaid work, aspects of the "volunteer" work of the patient and family are depended upon by the medical professionals. This includes "cooperation" with care in the hospital, even though it is not seen as work per se [9, p. 977]. In no situation is the concept of patient as participant as

obvious as in chronic illness, where the patient and/or the family clearly carry responsibility for ongoing care throughout the expanses of time between medical visits and hospitalizations. Chronicles of families in such situations have poignantly described their travails under these conditions [12-16].

It follows that the chronic illnesses of children, as illuminated by study of family interaction with medical institutions and interaction within the family and the child's world, provide further contexts for understanding corresponding divisions of labor. Critical focus on the dynamics of the developmental progressions in the children, as they advance beyond early childhood, enhances understanding of flexibilities and inflexibilities in the interactions relative to the patient's care over time.

In a study of 8 families, each with a hemophilic school-age boy, attention to their efforts to minimize health crises and to maximize benefits of medical protocols revealed extensive work in a series of categories. The variety of tasks within a range of circumstances were studied analytically. Aspects of child care responsibilities of families were examined in light of modifications as influenced by the chronic illness, the medical technology, and other social conditions.

The work of child care *per se* over time has been extensively studied [17]. More specifically, the nurturing of children for their survival, inherent in the care of the hemophiliac child, includes protecting the child from injury, seeking medical services, transporting the child for treatment, considering and/or pursuing changes in the course of treatment, managing

treatment supplies, and, indeed, enabling or supervising the child's relationships with teachers and peers in ways that enhance hemophilia care. These efforts extend to learning about the disorder and treatment modes, as well as teaching others about them to assure the patient's optimal health.

Children's developmental progressions within contexts of culturally determined social progressions, such as school entry, establish that dynamic circumstances are associated with shifts and changes in interactions around child care and self care. Dimensions highlighted in the study being reported here thus became sequences of child development over time and biographical events influenced by changes in social interactions and physical health.

Given that characteristics of illness trajectories also present specific dynamics for consideration [18], the relative stability of hemophilia and its treatment in this period of historical time, aside from intermittent emergencies, made it a "constant", so to speak, and thus an ideal condition for study of divisions of labor associated with child development and biography. The research illuminates the process of the transfer of medical and health-related tasks from the locus of adult responsibility to that of the child, particularly during the school ages. How this process occurs, and under what circumstances the transfer is incomplete are further detailed.

Method

The subjects, 8 boys with hemophilia, referred to the project at ages 7 to 13, were studied for a 5-year period through

participant-observation techniques, including interviews with the children in their homes, with the mothers, most of the fathers, several of the siblings, school teachers, and health care providers. Open-ended interviews, each approximately one hour in length, enabled data collection inclusive of the particular experience with hemophilia from the perspectives of the subjects and other informers, the perceptions each has of the meanings of the experiences to the hemophiliac children's peers, and considerations each has relative to the illness management. Successive interviews conducted with each hemophiliac boy drew upon data reflecting changes in social interactions and illness management that occurred as time progressed.

Additionally there were observations at school (in the classrooms and on the school playing fields), at the clinic, and at the summer camp for children with hemophilia. These observations specifically attended to interactions that were problematically associated with hemophilia management.

The interviewer chose to pursue the inquiry primarily as an interested home and school visitor. Direct participation was most specific in this role during the two sessions of the annual summer camp for hemophiliacs where observations were made. The researcher became a member of the adult staff, particularly to help the children develop a camp newspaper and participate in other crafts, while incorporating observations of the total experience for each of the subjects. Becoming a part of these children's daily lives under these circumstances for one week at a time provided an intimate vantage point within the context of

specific interactions.

Other observations were conducted from "distant" areas of classrooms and school playing fields, to make these as annonymous as possible, often to reflect the wishes of the subjects, but also to see "regular" interactions with as little research interference as possible. The observations were not infrequently topics for discussion during preceding and following home visits.

The mass of data, collected through transcribed tape recordings of interviews and process notes on observations, were categorized according to dominant themes. Case comparisons followed, noting similarities and differences. Where uniqueness was coded, search followed for particular conditions associated with these. Often further clarifying information was culled from succeeding interviews, as analysis was coincidental to the data collection itself. Associations and other relationships between aspects of the data were particularly noted.

In the analysis as recorded below, two distinctive categories in the work were seen as being linked: (1) who in the family, adult or child, becomes central in decision-making and responsible for the home-based medical work, and (2) when in the children's development shifts in management occur. Clearly, issues with regard to medical work emerged as major ones relative to the children's development.

Becoming Medical Technologists at Home:

The technically sophisticated work of preparing the medication, finding a proper vein for injection, and infusing the missing clotting factor, encompasses a teaching-learning process.

Over time, following initial diagnosis, the locus of this task moves from the medical center to the home, generally to a parent, albeit with medical supervision.

One mother described her learning and the associated interactions.

> I had done it once, trying it on myself, and I did it into my hand, and just as I was ready to pass out, I said, "I can't do this", so I was ready to really forget the whole thing. The next time we went to the hospital one of the nurses said, "Oh, come on, try it on me". And I had to dig and dig to find her vein and then the next time we went to the hospital, one of the technicians said to my son, "When do you think Mom is going to be able to do it?" He said, "She can do it now." And I said, "Okay". I tried and I found it and I just started crying, and I couldn't even move because I was so nervous. Then since it was a week-end and we would have to get interns at the hospital with no doctor on call, I decided I would do it at home. The doctor said, "Take it home, and if you can't do it, then come on in".

Another mother explained that a nurse had taught her to do the infusing; another described that a physician taught her the process; another mother learned through her professional training, although she explained how very different it is to treat one's own child than it was to start an IV on a patient in the hospital.

Errors or "misses" occur in the learning, as they do in medical personnel's learning as well. Everett Hughes' descriptions of "mistakes at work" amplify this concept and the consequences [19].

One boy, in talking about his mother's learning, commented to her,

> Last year, around September, you were trying to get in the vein, and finally the doctor had to get into the vein. You did once, but we had to go back the next day for another treatment. You couldn't get in.

He continued,

> Unfortunately, my mom doesn't know [about treating certain injuries] because I took a roller skate in the forehead and got a big bump and we never got it treated. The doctor said that it should have been treated.

The mother responded,

> We blew it on that, but it turned out to be fine.

The process of learning sooner or later leads to the ongoing work, based on experience, of home infusion. A mother described the process.

> It (now) takes about 45 minutes. It used to take a long time when I missed the vein and stuff, but I'm really good at finding the vein now, a lot better than I think I am. It actually is about an hour's procedure by the time I run it down and stuff, but we could do it anywhere. At first we had to go in the bedroom and have these lights, and now, if he is watching TV or if he is talking on the phone, all he has to do is lay down his arm. I still put the board on and still use the saline. He is waiting for me to grow up so I don't have to use the saline. I like to know that I have it before pushing the needle in.

The Massies' chronicle of their son's growing up with hemophilia described how the father was the initial person in this family to learn the infusing technique [16]. However, throughout this study, the mothers were the parent infusors.

The shifting of the locus of care from a medical person to a parent varies in timing and includes a back and forth exchange of this management, especially during the transition. Most often this shift occurred in the pre-school years when the child had developed sufficient understanding for at least a degree of cooperation, thus enabling parental control of the situation. Despite the parents' taking on the care, treatment at the medical center may substitute when under certain social and medical

circumstances, the treatment cannot be performed at home with ease.

The parents achieved proficiency, (that is, their ability to manage the techniques of treatment with sufficient ease so that they do it in less time than do new learners) becomes a modifying condition for instituting the children's learning. Parents recognize that the treatment time will again take longer, for the children must practice and learn the techniques until they, too, are proficient.

Teaching them the techniques of care generally remained the work of the medical professionals, with each mother usually guiding or encouraging this teaching-learning when she perceived that her son was "old enough". Respondents generally agreed that the teaching of the boys is done most easily when the teacher is outside the family. Thus the shifting between home and health center continues, with different "players" becoming central at home. The process of shifting is gradual. A 7-year old explained,

> I got myself the needle and mixed in everything, but I didn't put it in. I put it in his (the technician's) hand. It's easy to do that.

This boy achieved success in managing the full process at age 10 at the Hemophilia Camp, where he was congratulated at becoming a "first timer".

The method of learning a little at a time was reported frequently.

> At camp they got the needle in for me and I pushed it in and took it out.

Another said,

> At home Mama does it most of the time. I could put it in. Mama was standing there and watches.

While the mothers still manage most of the process, the boys, as they get a little older, may give direct advice or help with preparing the medication. A mother reported,

> Like when I'm mixing the medication, and the needles don't act right, I say, "Billy, what should I do?" and he tells me and it works.

Another mother, in thinking about her son's developing the infusion skill, said,

> Maybe just the mixing the medication up, and the sterile technique that's involved would be a help. He has done it once or twice, but the times were so spread out. I'm kind of waiting for him to express more of an interest in doing it himself.

Another mother reported,

> He hasn't been doing it totally by himself because sometime he doesn't want to do it, or it all depends on the time, and then I'll go ahead and do it.

Regarding one of the older school age boys, the mother commented,

> Now that he is older he can handle most of it himself. The school called me a couple of times and when he came home, I, from work, talked him through his infusion over the phone. Before I was working and when he was younger, then they would call me and I'd go pick him up.

The boy, however, clarified,

> I don't really like giving the injections, but I can. I get nervous, and if my Mom's home, she will give it to me. But, if I really need it, sometimes if it is really hurting bad, I take it.

Another of the older boys could take his first trip away from home with his new ability to give himself the infusions. A mother explained,

> He did it very well right away and then I guess the time he got sick, I did it, but then he started doing it again, and he has done it ever since. He does it

all himself now. The only thing that I do is help him with the tape and he can even do that himself, but it's faster if I just do that in the morning. It's just a matter of saving time. If I weren't here, he could do the whole thing.

A 12 year old boy's recently gained proficiency with independent treatment enabled his participation in activities for two weeks at two camps, only one of them being the hemophilia camp. At one he infused himself after he pulled a muscle in his leg, and at the other he infused himself after hurting his shoulder in a game.

Overlap of the work of experienced persons with the boys' efforts prepares for an eventual end to the transition. Sequential stages following mothers' learning are: (1) from mother-infusor to mother-infusor with child practicing; (2) to mother-infusor with child infusing on occasion; (3) to child-infusor. A graphic simile of the process is a balance scale with weight tipping to one side, then shifting to a near balance, to motion tipping slightly one way or the other, to a tipping on the other side. Shifts thus occur in divisions of labor and the consequent interactions.

Becoming Peer Group Members away from Home

The foregoing is presented as a major contrast to another aspect of self-care, a near opposite of the balance scale simile. Paradoxically, concurrent with the process of learning the technical skill for this aspect of treatment, a speaking up for oneself may not occur. This is true particularly in interactions with peers and non-parent adults which call attention to the hemophilia and the limits the disorder places on activities.

Whereas general progression occurs in one realm of care, a seeming reversal occurs in another. A broad overview of parent interventions in terms of "speaking up" about the hemophilia in school situations will be discussed below.

Remembering the early years, one mother spoke of her son's beginning his experiences in a pre-school. She made herself regularly available for certain activities.

> I really got the feeling that they really didn't understand exactly what could happen to him, and at that time I did not have coverage (home care inclusive of infusing the missing clotting factor). It was still the time when we were going to get cryoprecipitate so he could be injured severely without them even knowing how severe it was, without somebody there...I trailed along with the class.
>
> I told the teacher that if any day they were going to go to the playground, please tell me so I'll go with them. I knew that she knew he had to be protected, but she didn't really know.

Here is a reflection of direct monitoring by the parent at school. Developmentally, the child at this age may not be entirely "reliable" in monitoring for injury and reporting of pain.

Another mother became a teacher's aid in her son's school when he entered the elementary grades. She made herself immediately available when hemophilia explanations were required, and would take her son to the hospital when he was injured. She talked about how she would know when these interventions were necessary, as she would hear her name called on the loud-speaker. Working parents, less available in such circumstances, modified child-care plans to a certain degree, tentatively assigning their roles to others. A father explained his lobbying efforts at the first school his son attended when he asked that the teachers

monitor the hemophilia needs.

> I went and I talked to the principal and then the teacher. The first school wanted to put him in the retarded school, a handicapped school.

He changed schools for his child to one in which he felt he could rely on teacher-monitoring.

His son added,

> Mom and Daddy told the 2nd grade teacher. The second grade teacher told the 3rd grade teacher.

Almost every mother in the study visited her son's school at the beginning of each school year. One explained,

> I would tell the teachers [in the early grades] before school started. The last couple of years [son 11 at the time of this interview] I have told secretaries, and let the teachers have a day or two, and then I go and talk to them to make sure that they have gotten the message and that it's in the file and that somehow they know.

When another mother said, "I haven't yet determined who all we will tell next year as (her son) goes on to junior high", the boy interjected, "Tell all my teachers."

Still another mother who goes to school each "first day", felt she didn't need to repeat this the following year, as her son was about to enter the 7th grade and the teachers would be the same. However, as the following year began, she realized that there was a new teacher to whom she planned to explain the hemophilia needs.

In view of such lobbying or intermediating efforts on the part of the parents--particularly as the boys were beginning to learn the technical aspects of their own care--it is notable that concurrently, hemophilia explanations by the boys to peers and teachers at school became somewhat modified or completely

altered.

Early explaining to peers, especially in school, is often done in conjunction with their mothers' work. One boy stated,

> A couple of years in lower grades me and mom brought in all the equipment and showed it. We explained this needle stuff and my arm, and the medicine goes in, and the tourniquet made my veins show.

Then as a fourth grader, this boy began to refuse to partake in the "show and tell" his mother had initiated. When the mother of another boy presented the idea of having a person from the medical clinic do a hemophilia-explanation session for the class, her son's response was, "I'd be absent from school that day".

Thus, changes gradually occur in the boys' sharing of information about hemophilia, particularly with peers. A phrasing of the mother of a sixth grader exemplifies this:

> When he was younger anyone could ask and he would go into detail, but since he's gotten older, I guess he's tired of the same thing over and over, so he doesn't answer them any more. Like there are a couple of new students, and he won't tell them. The other students tell them, or he figures it's his business and not theirs. That could be it.

The boy claimed he never talked about hemophilia with peers, but then clarified this to acknowledge that it was "ages ago" in the first grade. The mother counter-claimed that he explained his condition at school up until the fourth grade.

Another mother reported a sequence of events relative to her son's special education program. This included a special teacher's coming to school to help the boy develop better motor coordination skills to support greater social participation.

> They do things like basketball. Well he had this thing going on with his finger, and I wasn't sure if she was coming every week because it has been sporadic. Jonathan had this bleed that started in his finger and

> we treated him for it. It seemed to be getting better the next day when he went to school. This lady came and I guess played basketball with him. The next day he needed another treatment. The finger was definitely worse. I said to him, "Did you mention to her that this was a sore area and the basketball playing might not be a good thing to do?" And he said, "No, I didn't say anything".

One of the oldest boys, when asked about his problem, said he responds with "shut-up". Still another of the older boys described that he begins a very technical, cognitively sophisticated discussion about missing clotting factors, following which his peers, with humor, stop his "lecture". His sharing of information is masked by his talking over the heads of his peers.

A shift became evident in the ways these boys would interact outside the family, especially at school, relative to hemophilia or its management, usually about mid-way in these school age years--around the 4th grade, ages 9 or 10. However, this does not mean that they were not sensitive to the perceptions of their peers earlier.

> In second grade I knew it for sure. I came to school a couple of times on crutches. My mom had told my teacher that I had hemophilia, but I wasn't going to school unless she told my teacher about the crutches. I was sort of embarrassed. You go to school on crutches one day, and the next day you have a shot and you go to school without crutches and all the kids were going, "you fake" and all that.

One of the younger boys, who no longer makes a formal presentation to his class as was described earlier, felt that his peers used to think he was "faking" it. When seeing the crutches, they would ask, "How did you do it?", as if he had suffered an accident.

Cognitive levels and breadth or limits in perceptions

influence all children's questions. However, the perception of being misunderstood or negatively regarded by peers was evident in the middle-childhood years. Thus,

> Everybody knows (about the hemophilia). They believe me, but you know it is just wierd to them.

Or as the mother said of her young son's peers,

> I don't think they really understand, but it's accepted.

An older school-aged boy explained,

> They don't know what I'm talking about so they leave me alone. They just understand they can't sock me or anything.

Relative to the acceptance by peers, albeit with limited understanding, a mother surmised,

> They have a real rough-tough image, but when it really comes down to it, they really do care. When they are playing sports and they are out to win the game, that's one thing. But playing or fooling around in the neighborhood, they do really watch out for him. They care and are protective of him.

Another mother enlarged upon this issue by describing a set of occurrences at school, in comparison with behaviors when the boy is playing with friends in the family's swimming pool.

> At home, he has a lot of freedom to be rough and jump in the water. When he's with his friends in this activity, he is comfortable without being rowdy.

However, every boy in her son's classroom had signed up to be on a touch football team, but he didn't want to be the only child who could not play. So, he signed up, too, rationalizing later that he actually does play this game with his friends during recesses. However, an alarmed principal, in consultation with the mother, prevented this participation on the team. The mother reported,

> He was in tears when I suggested that maybe it wasn't a good idea. When you form into teams, I get the impression that there's a little more pressure on you to be good, to win the game.

This could be compared with the comments made by another boy,

> The people that it gets rough with, I just don't play with, so I try to avoid them and play with those people that know that if I get hurt it is more serious. I think they play just as hard, but they still watch out.

Basic premises relative to small group interaction and the participatory features associated with small groups [20], as compared with the larger school groupings and its social pressures were supported throughout the data. Here, however, self-selected associations enabled interaction beyond that observed in the larger group contexts. The qualities of interaction in which the hemophiliac children participated were directly related to the size/intimacy features of the groups.

The data thus suggest a process of development and its effects on several of the self-care issues of chronic illness during childhood. With the children's growing understanding about themselves and growing capabilities in their medical treatment management, there is evidence that they become particularly self-conscious in the out-of-family, non-primary groups to which they belong. This is modified in self-selected friendship groups, essentially in their being "family-like" in terms of accepting the hemophilia disorder and its limitations.

One "negative case" was reflected by a 6th grader who presented a speech at school in an "I Had a Dream" contest, in which he explained his hope to find a cure for hemophilia. Perhaps he was less self-conscious because his hemophilia is mild and he is less different from others. His more "open"

interaction was unusual among these hemophiliac boys.

Siblings' Work--Further and Concurrent Divisions of Labor [21]

Siblings' work is conceivably the most hidden. With the amount of attention and work required in the care of the hemophiliac child, "fitting it (the care) in" amounts to neglecting in various ways the "other childen". Child care requirements, with modification relative to extra attention for the chronically ill child, apply to siblings, as well. A comment by an adopted sibling surprised her parents. In an intimate family moment the mother said,

> This will be the seventh Christmas that we've had you, that you've been our sweet little adopted girl.

The child thought about that and said,

> Yes, and I know why you adopted me...Because if you had had another child with hemophilia, you don't have enough hands to give treatments at the same time to two children.

If nothing else, the siblings' work is related to standing back to allow the care that the hemophiliac's treatment encompasses.

Siblings report on going for medical supplies, bringing homework to their brothers when they are absent from school, calling for help when there is a bleed, and advising their brothers on activities and when to go for help. Some report that they almost always go with their brothers for clinic visits or treatments. One described,

> Sometimes the whole family would go to the hospital. Sometimes my mom and grandmother and me would go. When Tom had cryoprecipitate, every time he went to the hospital, basically I was at the hospital with him.

Monitoring by a sibling also can occur: When a hemophiliac

brother was hurt at school, the sibling commanded, "Go home and get treated".

Another sibling described how she watched her brother (1 1/2 years her junior) at recess time. At times she would apply ice to his swollen joints if injury took place at school. At other times, when he was too young to go on the bus alone, she accompanied him on trips to the clinic for treatment. The mother of these children said,

> Dorothy never was a baby. She helps me when it comes to infusions because sometimes the needle doesn't come out right, or the bottle is too big for my hand. Sometimes I have a problem and then I will tell her to hold that while I pull the needle out. She knows if I say, "Get everything ready". She knows what to do and how to do it. She doesn't know how to stick him, of course.
>
> She knows when he has a bleed. When I'm not here, he talks to her. If he gets hurt at school, she tells him to go home. If he detects a bleed when at home, she tells him to stay home from school.

Siblings are sometimes "sitters" for their hemophiliac brothers, sometimes even when the sibling is younger. This can involve occasional high drama:

> Mom and Dad were at a dinner down at City Hall and my brother was hurting and he was crying. I asked him what he wanted, and he said, "Run down to get Mom and Dad. So, I ran down there and my mom came up and she gave him a shot, and my mom was saying, "Watch for him."

And:

> Our parents weren't home, and we had to take our brother to the hospital because he was bleeding again (a couple of weeks after a tonsillectomy). We tried calling, but we had to go to the hospital real quick. My friend's aunt drove us over. Finally my parents came and my brother had to stay in the hospital because he lost so much blood.

The siblings thus take on roles generally designated for adults. As the children extend the work of their parents, there

are transitions in learning and approaching these roles. These siblings also become self-conscious about having brothers with hemophilia, and accordingly need to consider their interactions with their own peers during these sensitive periods of growing up. Their age-related concerns about peer group membership are not unlike those of their chronically ill siblings.

Summary, Implications and Recommendations

The findings as presented here focus on the division of labor in the home-related care of children with hemophilia, with a refinement of understanding the changes in these divisions that occur as a result of children's development during the school ages. Whereas earlier studies have concentrated on the work of patients and families in the management of illness [22], this study illuminates those efforts in the context of a child's becoming sufficiently grown up to engage more in self-care activities, while still being reliant on others for aspects of his care.

A sociology of childhood describes a lessening of dependence on parents as children develop self-care skills in the school ages. The hemophiliac children become increasingly able to depend on themselves for aspects of their care relative to chronic illness as well as to the more ordinary tasks of daily living. The children's lives become more centered on school than home-family interactions, if only the amount of time spent in each of these institutions is considered.

In general, as well as in the case of hemophilia, changes in technical development modify treatment and influence divisions of

labor; coincidentally, there are shifts from the medical care institution to the home to accomodate the modifications in practice and the development of the child. Subsequently the locus of care changes from the adult-caregiver at home to the child in his milieu. Eventually, the child will translate or even transform the self-care to be in keeping with his developing perceptions and awarenesses of himself.

In short, along with intellectual and physical development, the child becomes more adept at handling technical tasks. From an adult perspective, these technical tasks are more difficult than are certain social tasks, especialy those setting one apart from peer norms, that the child begins to avoid.

Differentials are evident between the goals of adults' work and children's efforts. The growing self-consciousness of the children influences their interactions. To be different from peers, or to be perceived as being different, becomes a social risk which they would rather not take. Thus taking physical risks by not tending to medical problems becomes the child's preferred goal. Protection from physical injury may highlight difference or comprise deviation from group norms, whereas full participation masks differences. The significance of the peer group relationships to the school-age child, accordingly, was underscored in this study.

Families equate peer interaction with normal development, and are usually eager to support this aspect of their children's lives. Social intermediating by some family member, usually an adult, thus emerges. Parent-teacher conferences, for example, focus on these interactions from the perspectives of the boys.

The intermediate person is one who knows the boy intimately, and who can, "behind the scenes", enable the children's interactions via particular explanations. As one might expect, however, such interactions reflect only some parental styles. Health professionals aware of the parental styles that do not incorporate such intermediating can intervene accordingly.

The explanations at a given moment are most often related to the circumstances of a child's physical needs. This may be a day-to-day reporting so that a new issue, such as an injured joint can receive prescribed attention or protection. Whereas the annual parent-teacher discussions are important, the more frequent exchanges of information could prevent certain physical injuries and negotiate an amelioration of social injuries. Given the self-consciousness of these developing children, the intermediatory-behind-the-scenes work must be sensitive regarding how the information is conveyed and with whom it is discussed.

Small group membership can be supported so that the child can be ensured of having accepting peer group interactions compensating for the lesser participation and acceptance in the larger school groups. The small friendship groupings are more likely than the larger school groups to "settle for less" in interactions, and accept more of the limitations of a member. Teachers can encourage other children in the larger group to participate with the chronically ill child in activities in which the latter can participate fully and well.

To predict subsequent developmental steps relative to the above issues as these children progress into high school and

beyond, it is clear that few adults are required to participate in peer groups with the particular intensity of a school-sports-orientation typical of school ages in our cultures. An older student or adult need only select other kinds of activities as major focii of social participation. How selections are made may encompass adult perspectives of protection, thus defining work accordingly. This is not to deny that special psychological circumstances during adolescent years may skew these kinds of interactions and thus the divisions of labor during this period. Although limitations may continue, the pressures toward risk-taking behaviors for social reasons ease as the child or adolescent enters the young adult years. Further study is necessary to confirm or refute this hypothesis.

Comparable data from studies of children with other chronic illnesses (diabetes and cystic fibrosis) support the applicability of this study to understanding divisions of labor relative to families with children with a wide variety of other diseases [22, 23]. However, until further study demonstrates otherwise, it might be assumed that with illness trajectories that are less stable than is hemophilia, particularly with those of a declining nature, tasks transfering or remaining with the adult, even with the medical personnel, may be the phenomenon corresponding with set-backs or decline.

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